

**NPM #2: The percent of children with special health care needs age 0 to 18 years whose families partner in decision making at all levels and are satisfied with the services they receive. (CSHCN survey)**

**Impact on National Outcome Measures:** Overall, the SLAITS survey found 66.49% of families are satisfied with the services they receive and feel they are partners in decision making. This is higher than the overall national result of 57.53% of families who report satisfaction with the services they receive and feel they are partners in decision making.

a) Report of 2002 Major Activities

**1. Information and Referral Services Satisfaction Survey—Direct Health Care Services—CSHCN**

Although the CSHCN Program does not provide direct health care services to children with special health care needs or their families, the CSHCN Program is committed to assuring families are satisfied with the services received from the Regional CSHCN Centers and LPHDs.

An Information and Referral Services Satisfaction Survey was sent to over 1,100 families of children with special health care needs who utilized information and referral services from the Regional CSHCN Centers or LPHDs during 2002. See Appendix 6, Information and Referral Satisfaction Survey. The results revealed an average satisfaction score of 4.662 on a 5.0 scale.

**2. Financial support to County Parent Liaisons—Infrastructure Building Services—CSHCN**

The CSHCN Program requires the five Regional CSHCN Centers to identify a CPL through partnering with the LPHD. Financial support is offered to CPLs to increase participation in activities that positively impact policies, programs and services attend educational workshops or participate in family centered activities in their communities.

**3. Employment of State Parent Consultant and Regional CSHCN Center Parent Coordinators—Infrastructure Building Services—CSHCN**

Parents play a central role in many aspects of the CSHCN Program. Parent involvement is supported through the continued employment of a Parent Consultant at the CSHCN Program. Parent Coordinators are employed at all five Regional CSHCN Centers. Parents are employed at the Wisconsin First Step Hotline to provide information and referral services.

**4. Participation of families on advisory committees to the MCH and CSHCN Program—Infrastructure Building Services—CSHCN**

The role of families has been strengthened as they continue to participate on the NBS Advisory Committee, Birth Defects Council, Universal Newborn Hearing Screening Work Group and the MCH Advisory Committee.

**5. Parent input into the MCH Block Grant Application—Infrastructure Building Services—CSHCN**

In 2002, parent input into the MCH Block Grant Application was requested from over 400 parents in attendance at the annual Circles of Life – Families Conference. A Workbook for Families regarding the MCH Block Grant was adapted and developed from a Family Voices publication and distributed with the public input invitation in order to solicit comments from family members.

b) Current 2003 Activities

**1. Information and Referral Satisfaction Survey—Direct Health Care Services—CSHCN**

The information and referral satisfaction survey is an ongoing survey that will continue throughout 2003 in order to assure the services, provided through the CSHCN Program, are meeting the needs of the families. A “2002 Annual Program Evaluation Report” is being developed and will be widely distributed throughout the last six months of 2003 that analyzes and summarizes satisfaction with the information and referral services received from the CSHCN Program.

**2. Financial support to County Parent Liaisons—Infrastructure Building Services—CSHCN**

Financial support is being provided to over 50 CPLs to continue involvement in activities that positively impact policies, programs, services and supports regarding children with special health care needs.

**3. Employment of State Parent Consultant and Regional CSHCN Center Parent Coordinators—Infrastructure Building Services—CSHCN**

The CSHCN Program continues to employ a Parent Consultant at the CSHCN Program. In addition, each of the five Regional CSHCN Centers employs a parent coordinator. The Wisconsin First Step Hotline employs parents with children with special health care needs to provide information and referral. There is continuing support for a CPL in each of Wisconsin’s 72 counties.

**4. Participation of families on advisory committees to the MCH and CSHCN Program—Infrastructure Building Services—CSHCN**

Parents are continuing to be important in the decision making process as they are active members of all four advisory committees in MCH and CSHCN including: NBS Advisory Committee, Birth Defects Council, Universal Newborn Hearing Screening Work Group and the MCH Advisory Committee.

**5. Parent input into the MCH Block Grant Application—Infrastructure Building Services—CSHCN**

We are increasing the number of parents providing input into the 2004 MCH Block Grant Application by requesting input from over 500 parents who attended the annual families conference called Circles of Life. A Workbook for Families that was adapted and developed from a Family Voices publication in 2002 will be distributed along with a public input invitation.

c) 2004 Plan/Application

**1. Information and Referral Satisfaction Survey—Direct Health Care Services—CSHCN**

The CSHCN Program will continue to assure families are satisfied with those services received from the Regional CSHCN Centers including information and referral, parent to parent support and service coordination. A satisfaction survey will be sent out to all families who utilize information and referral services during 2004 for planning for the CSHCN Centers contract for 2005. The information will also be utilized for the Title V MCH/CSHCN Program Block Grant needs assessment.

**2. Financial support to County Parent Liaisons—Population-Based Services—CSHCN**

Financial support will continue to be provided to CPLs to continue involvement in activities that positively impact policies, programs, services and supports regarding children with special health care needs.

**3. Employment of State Parent Consultant and Regional CSHCN Center Parent Coordinators—Infrastructure Building Services—CSHCN**

The continued employment of a Parent Consultant at the CSHCN Program, a parent consultant at all five Regional CSHCN Centers, parent consultants at the First Step Hotline, and the support of a CPL in each of the counties will continue throughout 2004.

**4. Participation of families on advisory committees to the MCH and CSHCN Program—Infrastructure Building Services—CSHCN**

Parents will continue to participate on the advisory committees in MCH and CSHCN including NBS Advisory Committee, Birth Defects Council, Universal Newborn Hearing Screening Work Group and the MCH Advisory Committee.

**5. Parent input into the MCH Block Grant Application—Infrastructure Building Services—CSHCN**

Parent Focus Groups occurring in the fall of 2003 will assist with gathering parent input for the 2005 MCH Block Grant Application needs assessment, as well as identify parents who are interested in reviewing the activities listed and provide feedback about the six core outcome measures.